

**211.577 Duties of council -- Report -- Response -- Hearing.**

- (1) The Kentucky Rare Disease Advisory Council shall:
  - (a) Act as the advisory body on rare diseases to the General Assembly, the Governor, and to all relevant state and private agencies that provide services to, or are charged with the care of, individuals with rare diseases;
  - (b) Coordinate its duties with those community-based organizations and private-sector institutions within the state for the purpose of ensuring greater cooperation regarding the research, diagnosis, and treatment of rare diseases. The coordination shall require, when appropriate:
    1. Disseminating the outcomes of the advisory council's research, identified best practices, and policy recommendations; and
    2. Utilizing common research collection and dissemination procedures;
  - (c) Research and determine the most appropriate methods to collect thorough and complete information on rare diseases in Kentucky and other information as the council deems necessary and appropriate to collect;
  - (d) Research and identify priorities relating to the quality, cost-effectiveness, and access to treatment and services provided to persons with rare diseases, and develop related policy recommendations;
  - (e) Identify best practices for rare disease care from other states and at the national level that may improve rare disease care in Kentucky;
  - (f) Develop effective strategies to raise public awareness of rare diseases in Kentucky;
  - (g) Ensure that the duties of the council are carried out in a manner that is coordinated and compatible with similar research being conducted at the state and federal levels;
  - (h) In conjunction with the state's medical schools, the state's schools of public health, and hospitals in the state that provide care to persons diagnosed with a rare disease, develop a list of existing, publicly accessible resources on research, diagnosis, treatment, and education relating to rare diseases; and
  - (i) Report biennially on its activities, findings, and recommendations relating to the quality, cost-effectiveness, and access to treatment and services for persons with rare diseases in Kentucky to the Governor, the Cabinet for Health and Family Services, and the General Assembly.
- (2) Upon receipt of the council's biennial report, the Governor and Cabinet for Health and Family Services shall within ninety (90) days issue a written response to the council detailing its efforts to improve state policies pertaining to the identification, treatment, and care of rare diseases.
- (3) Upon receipt of the council's biennial report, the Interim Joint Committee on Health Services shall within one hundred twenty (120) days convene a hearing on issues pertaining to the identification, treatment, and care of rare diseases identified by the council in its report.

**Effective:** June 29, 2023

**History:** Amended 2023 Ky. Acts ch. 25, sec. 23, effective June 29, 2023. -- Created

2019 Ky. Acts ch. 32, sec. 2, effective June 27, 2019.

**Legislative Research Commission Note (6/27/2019).** Under the authority of KRS 7.136(1), the Reviser of Statutes has modified the internal numbering of this statute from the way it appeared in 2019 Ky. Acts ch. 32, sec. 2.